

DMH Satisfaction Survey Results

Consumer Satisfaction - 2002

MRDD Family Forms and Family Directed Support

Demographics of Family Member Receiving Services

Person completing form provided demographics about their family member receiving services.

		Agency Survey Returns					
		Total Family Members	Case Management Family Members	Congregate Residential Family Members	In-Home Family Members	Supported Residential Family Members	Family Directed Support
SEX	Male	59.1%	47.1%	40.7%	65.4%	47.4%	59.8%
	Female	40.9%	52.9%	59.3%	34.6%	52.6%	40.2%
RACE	White	87.6%	83.3%	88.9%	77.8%	94.7%	87.8%
	Black	7.4%	16.7%	11.1%	18.5%	0%	7.0%
	Hispanic	1.2%	0%	0%	0%	5.3%	1.2%
	Native American	0.9%	0%	0%	0%	0%	1.0%
	Pacific Islander	0.7%	0%	0%	0%	0%	0.7%
	Alaskan	0%	0%	0%	0%	0%	0%
	Oriental	0.1%	0%	0%	0%	0%	0.1%
	Bi-Racial	1.6%	0%	0%	0%	0%	1.7%
	Other	0.6%	0%	0%	3.7%	0%	0.6%
MEAN AGE		23.55	42.09	51.50	39.75	36.72	22.12
	0-17	45.7%	0%	0%	8.3%	5.6%	48.9%
	18-49	45.2%	82.9%	41.7%	66.7%	77.8%	43.5%
	50+	9.1%	17.1%	58.3%	25.0%	16.7%	7.6%

Sample Size

Information is based on the number of interviews and the number of people served according to DMH billing records.

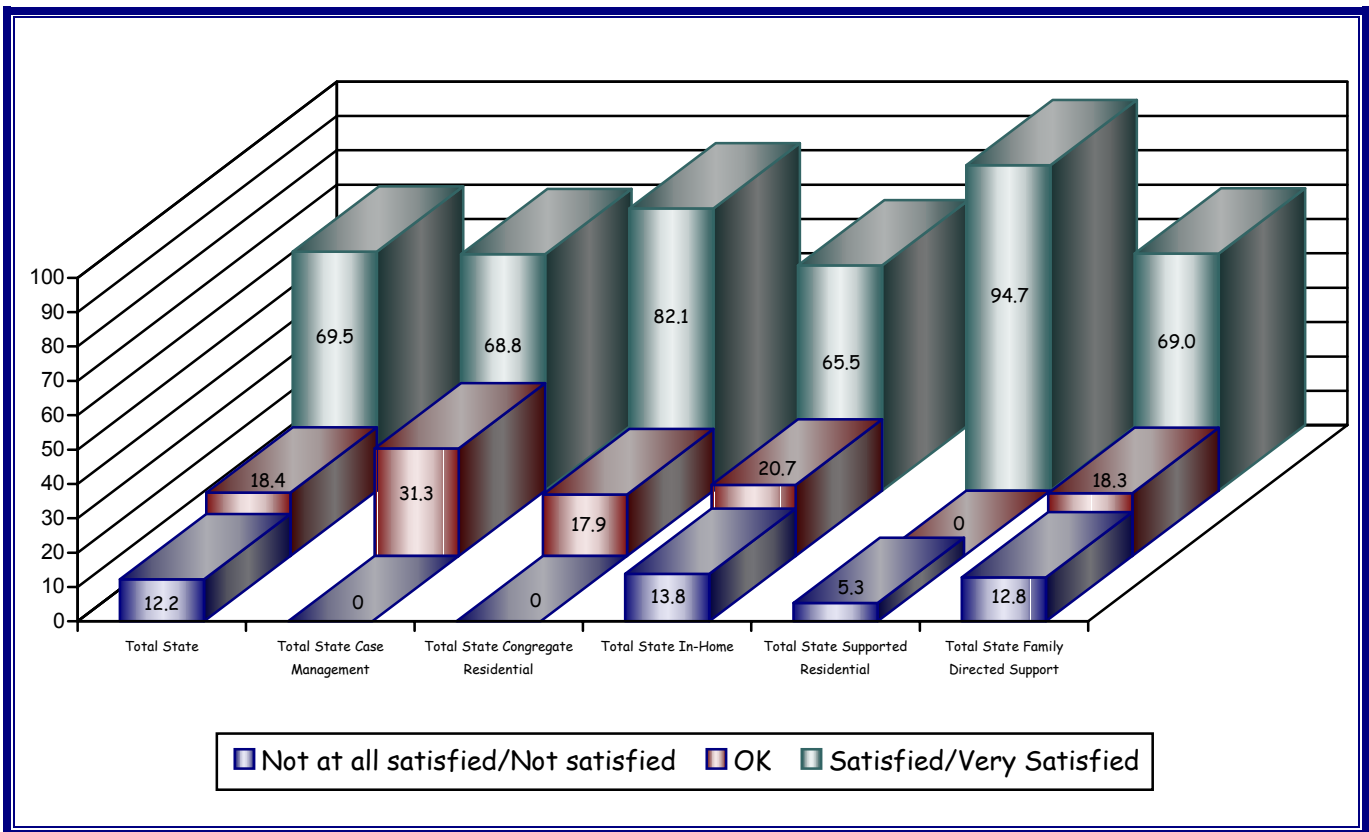
	Number in Selected Sample	Number of Surveys Returned	Percent of Forms Sent Returned
Total Family Members (Family Directed Support and Regional Centers)	10343	1531	14.8%
Total Family Members - Regional Centers Only	720	118	16.4%
Case Management Only	277	37	13.4%
Congregate Residential	119	31	26.1%
In-Home	208	30	14.4%
Supported Residential	116	20	17.2%
Family Directed Support	9623	1413	14.7%

Is Your Family Member's Life Better

One question on the family member survey addressed the issue of whether or not their family member's life has improved because of the services received. The following table shows the results of this question.

Is your family member's life "better" now than before s/he began receiving services?	Yes	No	Unsure
Total MRDD Family	1006 (70.4%)	171 (12.0%)	252 (17.6%)
Case Management Only	22 (71.0%)	1 (3.2%)	8 (25.8%)
Congregate Residential	27 (93.1%)	0 (0%)	2 (6.9%)
In-Home	27 (93.1%)	2 (6.9%)	0 (0%)
Supported Residential	15 (78.9%)	2 (10.5%)	2 (10.5%)
Family Directed Support	915 (69.3%)	166 (12.6%)	240 (18.2%)

Overall Satisfaction with Services



Program Satisfaction: Percent of responses to the question "How satisfied are you with the services you receive?"

Some of the key findings were:

- Statewide, 69.5% of family members of consumers served by the Division of Mental Retardation and Developmental Disabilities (MRDD) were "satisfied" or "very satisfied" with services.
- The Supported Residential group rated the program higher than other groups (94.7% "satisfied" or "very satisfied"). The Congregate Residential group also rated the services highly (82.1% "satisfied" or "very satisfied").
- The lowest satisfaction was in the In-Home program, where 65.5% of those served gave a "satisfied" or "very satisfied" rating.

Satisfaction with Services

How happy are you . . .	Total State Regional Centers	Case Management Only	Congregate Residential	In-Home	Supported Residential	Family Directed Support
1. with the people who are paid to support your family member?	4.10 (1374)	4.06 (31)	4.30 (30)	3.62 (26)	4.26 (19)	4.10 (1268)
2. with how much your family member's support staff know about how to get things done?	3.95 (1398)	3.90 (31)	4.14 (29)	3.67 (27)	4.26 (19)	3.94 (1292)
3. with how staff and/or case manager keeps things about your family member and his/her life confidential?	4.30 (1403)	4.29 (31)	4.38 (29)	4.21 (28)	4.61 (18)	4.30 (1297)
4. that your family member's plan has what he/she wants in it?	3.90 (1408)	3.93 (30)	4.17 (30)	3.79 (28)	4.33 (18)	3.89 (1302)
5. with how the case manager and support people are doing what your family member's plan says they should do?	3.98 (1422)	3.97 (32)	4.29 (28)	3.79 (29)	4.63 (19)	3.97 (1314)
6. that the staff who provide services to your family member respect his/her ethnic and cultural background?	4.33 (1305)	4.25 (28)	4.35 (26)	4.12 (25)	4.59 (17)	4.33 (1209)
7. with the supports and services that your family member receives from this Regional Center?	3.95 (1455)	4.09 (32)	4.29 (28)	3.69 (29)	4.53 (19)	3.93 (1347)
8. that services to your family member are provided in a timely manner?	3.86 (1461)	3.97 (33)	4.23 (30)	3.75 (28)	4.37 (19)	3.84 (1351)
9. with your family member's case manager?	4.10 (1466)	4.03 (31)	4.23 (30)	3.96 (28)	4.53 (19)	4.09 (1358)
<p>The first number represents a mean rating. Scale (items #1-9): 1=Sad/Not happy ... 5=Happy [Two additional responses were possible: "Do not understand" and "Does not apply to me"]. The number in parentheses represents the number responding to this item.</p>						

Some of the key findings were:

- **Statewide, family members of consumers served by the Division of Mental Retardation and Developmental Disabilities Regional Center programs were satisfied with the services they received. All ratings fell near a mean rating of 4.00 ("satisfied").**
- **Family members were most satisfied with the staff's respect of cultural and ethnic backgrounds (mean of 4.33) and least satisfied with services being provided in a timely manner (mean of 3.86).**
- **The Supported Residential family members were most satisfied with the services received (mean rating of 4.53).**

Satisfaction with Quality of Life

How happy are you ...	Total State Regional Centers	Case Management Only	Congregate Residential	In-Home	Supported Residential	Family Directed Support
10. with how your family member spends his/her day?	3.82 (1455)	3.82 (34)	4.23 (30)	4.11 (28)	4.26 (19)	3.80 (1344)
11. with where your family member lives?	4.38 (1400)	4.19 (32)	4.57 (30)	4.14 (29)	4.42 (19)	4.39 (1290)
12. with the number of choices your family member has in his/her life?	3.69 (1405)	4.06 (32)	4.29 (28)	3.71 (28)	4.44 (18)	3.66 (1299)
13. with the opportunities/chances your family member has to make friends?	3.59 (1424)	3.88 (34)	4.21 (28)	3.82 (28)	4.37 (19)	3.56 (1315)
14. with your family member's health care?	4.12 (1438)	3.94 (35)	4.41 (29)	4.41 (27)	4.47 (19)	4.10 (1328)
15. with what your family member does during his/her free time?	3.61 (1415)	3.79 (34)	4.14 (29)	3.83 (29)	4.16 (19)	3.59 (1304)
16. with the opportunities your family member has had during the last year to do something that he/she is proud of?	3.85 (1377)	4.03 (33)	4.04 (25)	3.82 (28)	4.33 (18)	3.84 (1273)
How safe do you feel ...						
17. your family member is in his/her home?	4.54 (1467)	4.42 (33)	4.54 (28)	4.29 (28)	4.72 (18)	4.55 (1360)
18. your family member is in his/her neighborhood?	4.25 (1451)	4.48 (31)	4.54 (28)	4.04 (28)	4.44 (18)	4.24 (1346)
<p>The first number represents a mean rating. Scale: (items #10-16): 1=Sad/Not happy ... 5=Happy Scale: (items #17-18): 1=Not at all safe ... 5=Very safe [Two additional responses were possible: "Do not understand" and "Does not apply to me"]. The number in parentheses represents the number responding to this item.</p>						

Some of the key findings were:

- The family member's responses to the quality of life questions indicated less satisfaction than their answers pertaining to satisfaction with services.
- Family members were most satisfied with safety in their family member's home (mean of 4.54) and least satisfied with their family member's opportunities/chances to make friends (mean of 3.59).

MRDD Families Subjective Responses

What was liked Best about the Program:

Negative Responses

When asked the question about what they liked best about the Family Directed support services a number of the responses were negative in nature. A number of surveys simply stated, *What support Services?* Several other surveys had comments related to the Case Worker or Service Coordinator, *never see our service coordinator, never hear from Regional Center Case Worker*, and another family member wrote, *Do we have a case worker?*

Family Can Choose

Many families indicated that the thing they liked best about the services they receive is that they can choose what the services and supports will be for their family. Families shared that being able to choose the services they thought were most beneficial was important because they know what's best for their family. Comments like the following illustrate this: *That we can choose as a family what we believe is needed for our family, That we could choose what we need, What we need is valid and we can get what we need, and We choose what we need.*

Services Received

Many family members stated that what they liked best about the services they received was a particular service. Services that families commented on were therapies, ABA, counseling, and Respite. Many family members indicated that they appreciated the services they received in this way: *ABA has taught her how to communicate and she receptively understands much more, The counseling she receives is effective, and The therapies we receive.* These are only a small sample of the comments made by persons whose family members were receiving services

Funding/Financial Support

Some family members indicated that the financial support they receive for the services they obtain on behalf of their child was very beneficial to them. Family members were specific in stating that the funding they received for equipment and therapy allowed them to obtain services that they may otherwise be unable to acquire. As one parent said, *the center helps us buy things for our child we couldn't afford otherwise.* Another parent stated simply, *funding for therapy*, while another wrote, *the financial support for therapy is wonderful.*

Staff

A number of survey responses indicated that families were pleased with the staff that provided direct services to their family member. Comments like the following illustrate this point, *I have never asked for anything that the staff at HRC has not at least tried to help me with. They all go above and beyond. Staff takes into consideration what he wants to do and staff enjoys him, and Staff is not afraid to call family for answers.*

Provider Agency

Many family members made comments about the provider or the agency providing services as the thing they liked best about the supports they receive. Some of the comments that follow illustrate that point: *The agency provides a family-style atmosphere and is committed to high quality care and Current provider has broad range of potential services for her.* One individual shared that what they liked was the opportunity they had to give their input into the services they received for their family member, *Needs are taken care of continue to have 1X a year meeting to see what family thinks.*

Case Manager

Many of the comments offered by family members were specific to the Case Manager/Worker. Written statements like the following show the satisfaction that many family member have in regard to their Case Manager: *We have a wonderful case manager with Regional Center. She keeps us informed and provides access to mailing lists and other service agencies.* Often times family members were particularly satisfied with their Case Manager's creativity in finding services and in their knowledge of the services available. *Service Coordinators are dedicated and creative and Case Worker offers options I would have not known about.*

Response Time

Another issue that was seen as an area that families liked best about the services they received was the timeliness of someone to respond to their questions and address problems that arise. Surprisingly when families talked about timeliness it was in regard to questions asked and problems resolved and not the timeliness by which their services were received or implemented. Family members made statements like, *Timely answers to my questions,* and *The response of the service coordinator when problems arise.* Other comments like, *They always call me back right away when I call with a question and jump right in to resolve problems quickly,* were other statements made in regard to the timeliness of someone to respond to a family's needs.

Respite Care

Respite Care was mentioned numerous times in the Family Directed Support satisfaction surveys. Many families indicated that respite care offered them opportunities to engage in social activities as well as provided them the support they needed in emergency situations. When asked what they liked best about the services they received families said, *Respite Care in the case of emergencies, We receive respite care reimbursement (when we get it) this allows us to nurture other personal and social commitments, My child receives respite services from regional center. This allows my husband and myself time to ourselves, knowing someone we chose is taking care of him and We appreciate having someone look after K_____ when we are out of town.*

Independence

Many individuals indicated that what they liked best about the services they received was the personal independence that the family directed supports provided to them. *I like the freedom it affords me to move around and get things done independently.* It was evident from the comments made by family members that living in a more independent setting impacted an individual's life in a positive way. *It allows him to live independently and gives him a better life than in a nursing home and He gets to live on his own now and that has made all the difference - he's found his independence.* Other family members expressed that what they liked best about the services was the opportunities the supports offered that increased a person's independence, *helped him gain more independence.*

What Could Be Improved:

Transportation

One of the services that families indicated needed to be improved upon was Transportation. In some cases there is no transportation at all and in other situations the transportation that is available is limited and inconsistent. One person said that, *We were hoping transportation would become available in some way but that hasn't changed.* Several other individuals wanted transportation to and from work, *transportation to and from work.* Another person expressed their displeasure in being charged for transportation that sometimes doesn't even show up. *I don't like that you are being charged when her ride never shows up.* Numerous surveys simply had the word *transportation* written in the space that asked the question about what services needed improvement.

Residential Settings

Many of the surveys indicated specific services that people believed needed to be improved. Residential programs were mentioned numerous times. Some people wanted more group homes while others simply wanted some type of residential placement for their adult family member. Still others wanted more residential options in their area to choose from. Comments like, *More adult supervised group homes available, Assistance to find a home for our daughter while we are still alive to help her make the transition, a nice, clean apartment for my daughter to move into, more residential programs to choose from in our neighborhood, and More community living options* illustrate just some of the issues family members believe need improvement in the area of residential settings.

Employment

Another specific service that families believe need improvement is employment. Many family members indicated that support with employment would improve the services they currently receive. *Employment would be a big help.* Others indicated that they had been waiting for support in this area for a long time and little had been done in this area. *My daughter has been waiting for a job for 5 years. All we hear is promises and We really want J_____ to have a job and we've been waiting for help for a long time and nothing changes he still hasn't got a job and its been forever.* One person indicated that *Employment would be a big help.*

Respite Care

Respite care was another service that families discussed specifically as an area that needed improvement. Some indicated they wanted more and others commented on the lack of funding for respite care as something that needed improving. *Could use some respite and Could do more to help the parents in the family with some respite.* Some families had ideas of how they would like respite to be offered. One

family suggested that MRDD *Allow respite hours to accumulate throughout fiscal year so family could use together for vacation (this is done in St. Louis)*. Another family wanted a list of respite providers in their community, *Would like a respite provider in our community - I think DMH should supply provider list in price range DMH will reimburse*. Another suggestion was to increase the number of respite beds in group home settings, *Have more Respite Care Houses*. There were many surveys that simply had the word *Respite* as an area that needed improvement.

Staff

Issues regarding staff were another area in which many individuals commented on the need for improvement. Several indicated that staff wages were low and they needed to be increased to keep good workers. *Staff need more money so more staff will stay working with the mentally disabled, Pay his aid more money and better benefits, and Assure that the direct caretakers are recognized and compensated well!* Other statements about staff had to do with ensuring that employees improve upon their specific job responsibilities. For example, several individuals commented on wanting staff to keep residential settings cleaner. *Staff could keep the house cleaner and Providing house live-in staff to come in and take my son to outing while house person cleans house* illustrate these concerns. Other comments by family members indicated that staff turnover was problematic particularly when it came to consistency and achieving outcomes. The following are examples of such comments, *Staff turnover rate with employees which greatly effects the continuity of care and communication* and *Our service coordinator has changed several times delaying the accomplishment of goals*.

Services Limited / Funding Caps/ Limited Funding

Many families had concerns about funding limitations and the availability of services. Some individuals expressed their frustration with the lack of funding available for their child to receive services even though they qualify for services, *It makes me angry that my son qualifies for all sorts of funding but there is hardly any available for him and Does not receive the services entitled to*. Other individuals had these comments about the lack of funding available to them, *Family Directed Support provides nothing, I'm always told 'no money'/'no time', We've had 4 requests - 4 denials doesn't seem like we are getting a whole lot of help, DMH needs more money to be able to help with other needs, and Money made available to pay for a communication device for my son*. Several families spoke about the frustration they felt when they hear about budget cuts. *There is too much discussion about budget cuts with the clients. Many are limited in what they can understand about a budget cut. Case Managers should only discuss what services are available and not talk about what may or will be cut in the future. This causes much distress for the client involved*. Other families simply expressed their desire for continued funding, *Continue services as children get older, There is a \$5,000 cap on ABA therapy. We would like to see that cap lifted. ABA is the one thing working for our daughter, and To be able to count on funding being available*. For some of the families who filled out surveys there was a frustration in not getting the services they thought they were going to receive when they began the Family Directed Support Program. *Definitely NOT what we were lead to believe would happen when we entered the program*. Several surveys indicated that some families were not receiving any services at all. Comments like the following illustrate this issue, *We have not received services in Seven years, Never hear from our worker - we don't even have a plan anymore, We've tried to get services but our worker never calls us back*.

Overall System Changes

When asked how services can be improved many families made suggestions that seemed to be geared towards a system wide procedural change. Families expressed a desire for more flexibility, individualization of services, and timelier updating of information. Families had this to say about individualizing services, *By supporting individual needs instead of trying to fit everyone in particular slot*. Another individual believed

that the system needed to go back to being more flexible, *Go back to being more flexible - Trust that I need what I say. I do not ask for ridiculous or outlandish services.* Equity within the system was also mentioned as an area of improvement, *Equity is needed. My son qualifies but receives nothing while others of less need continue to receive aid.* On the issue of timeliness there were several statements made by family members that indicated that records needed to be updated more frequently. *Need to update information in a more timely manner. They believed his father was alive, died last September, and My son died 3 years ago you people need to update your records.*

Case Worker Involvement

Many of the survey respondents indicated that Case Worker Involvement was an area that needed to be improved upon. Several families shared that they had never even met their case worker, *Case Worker has never met with family or client - I must initiate everything usually to no avail,* while others stated that the only time they saw their case manager was at the yearly meeting, *The only services is the once a year refilling of the support plan - Medicaid is billed when I fill out the paperwork. The case worker does not contact us or find ways to support the consumer in the plan!* Other comments about case worker involvement indicated that often times family members were frustrated because of the lack of contact they seemed to have with their Case Workers. *I have attempted to contact my son's service coordinator several times but have gotten no response. As a result I believe his support services have lapsed, Service Coordinator have more contact with the client, and More efficient service coordinator - The time lapse between contacts has been months at a time and I ask for documentation forms and I get them weeks or months later. We missed 4-5 months of reimbursement last year (2001) because of this.* Other family members simply wanted more contact so they could be better informed of services *More contact between case manager and parents - to be informed of services that may benefit my child that we may not be familiar with.*

Implementing Plan

Another area in which families indicated needed improvement was the actual implementation of the service plan. Families commented that often times while the plan would be written, implementation of the plan was problematic. One individual said, *We are pleased with what's in her plan but nothing is getting done. We were lead to believe that we could direct what our family member needs to make her life better - but actually we have no control.* Another family member had this to say about the implementation of a service plan, *T___ wants to learn how to drive. And I believe this was included in hab plan. No action taken yet!* Other comments about the lack of implementation of service plans were as follows, *When plans are written they should follow up to see if they are being carried out, and Getting the services outlined in our service plans.* Several other respondents to the survey indicated that while the service plans were being implemented the time between creation and implementation seemed excessive. *Services set up in the plan - more timely manner. Plan has to go through too many people, committees, and hoops to get put into action! Person has to wait what seems like forever before getting services started.*

Community Involvement

Some of the family members who responded to the satisfaction survey believed that services could be improved by increasing the number of community activities available to consumers. *More opportunities in the community, More community integration, Get them involved more in the community, and Client needs more opportunities/activities in the community.* In addition to community activities and increased involvement some family members expressed a desire to see consumers connect with friends, particularly individuals who are not paid to be with them or who do not receive services as well. *Connect with friends who aren't paid to be with him and Help him make friends with people outside of his disability world.*